

December 2007

A Grounded Theory Investigation of Patient Empowerment in E-Healthcare

Sherrie Cannoy

University of North Carolina, Greensboro

Follow this and additional works at: <http://aisel.aisnet.org/amcis2007>

Recommended Citation

Cannoy, Sherrie, "A Grounded Theory Investigation of Patient Empowerment in E-Healthcare" (2007). *AMCIS 2007 Proceedings*. 414.
<http://aisel.aisnet.org/amcis2007/414>

This material is brought to you by the Americas Conference on Information Systems (AMCIS) at AIS Electronic Library (AISeL). It has been accepted for inclusion in AMCIS 2007 Proceedings by an authorized administrator of AIS Electronic Library (AISeL). For more information, please contact elibrary@aisnet.org.

A Grounded Theory Investigation of Patient Empowerment in E-Healthcare

Sherrie Drye Cannoy

University of North Carolina Greensboro
Information Systems and Operations Management
PO Box 26165
428 Bryan Building
Greensboro, NC 27402
336-256-0192
sdcanoy@uncg.edu

Abstract

Emerging technological innovations such as electronic health records (EHRs), regional health information organizations (RHIOs), and the nationwide health information network (NHIN) have enabled increased sharing of medical records in the healthcare community. Recent studies have shown that patients do not trust their healthcare providers to keep their medical records safe from unauthorized release. Patients seem to have focused their attention on negative media stories of information disclosures, both inside and outside of the healthcare community. The same studies revealed that patients want more control over the access to their medical records. Therefore, the notion of patient/consumer empowerment has emerged within the healthcare community's discussions regarding the sharing of medical information and development of policy and technological innovations. In this research, the facets of patient empowerment in e-Healthcare will be investigated through a Grounded theory approach to analyzing documents from both United States federal and state patient empowerment groups.

Keywords: patient, empowerment, healthcare, grounded theory, privacy, security

Statement of the problem

The United States healthcare industry is currently experiencing a technological transformation. Due to recent technological advances, information can be shared among many healthcare providers with the goal being reduced medical errors and increased quality of care. With U.S. legislative mandates and calls for the adoption of a Nationwide Healthcare Information Network (NHIN), RHIOs (Regional Health Information Organizations), EHRs (Electronic Health Records), and PHRs (Personal Health Records), the awareness of patient empowerment is emerging. A survey by the California HealthCare Foundation (Broder, 2006) found that most consumers want to have control over who accesses their medical information and that only three percent used an online medical record service. Janlori Goldman, privacy advocate and member of the Health Privacy Project (1999) calls for a “reversal of the technological status quo by demanding that technology be designed to empower individuals” by shifting the balance of power between “the individual and those seeking personal information” for example, through giving control of medical information to the patients. “Since this [PHR] approach empowers individuals to control all access to their own health information, it gives each consumer the freedom to establish their own personalized privacy policy” (Enrado, 2006) and decide how it will be shared across organizations such as the Regional Health Information Organization (RHIO) and U.S. Nationwide Health Information Network (NHIN), both of which enable the infrastructure for sharing patient information across organizations such as hospitals and provider offices. From the literature reviewed in the healthcare, marketing, management, information systems, and sociological realms, it was found that patient empowerment has many dimensions and no well-defined theory for conducting research studies in e-Healthcare.

Research Questions

Based on the preliminary analysis of consumer empowerment literature and the recent interest in the issues of consumer empowerment in societal venues, the following research questions are posed for this study.

1. What does it mean to be an empowered healthcare consumer?
2. How do the perspectives of the stakeholders involved in e-healthcare affect consumer empowerment?

For the purpose of this study, e-Healthcare is defined as the sharing of patient information in EHRs and PHRs among organizations through a RHIO or NHIN network.

Literature Review

Given that empowerment is the central focus, definitions of empowerment are drawn from healthcare, management, information systems (IS), marketing, and sociology research streams.

From a managerial and IS perspective, the emphasis on modern empowerment began in the late 1980s through the creation of teamwork and employee involvement in innovation efforts to ensure company profitability. For example, participatory design in information systems and knowledge management were key IS issues which were to empower employees while also creating a more efficient and profitable firm (Sjoberg et al, 1998). In the e-Healthcare context, the lessons for participatory design and knowledge sharing for innovation can be utilized to provide feasible and user-friendly PHRs by conducting an examination of what features and capabilities the patients want from PHR technology. The aspect of

empowerment in the marketing literature focuses primarily on the concept that consumers can enforce their power through marketplace economics (Shaw, Newholm, and Dickson, 2006; Wathieu et al, 2002). Shankar et al (2006) state that the lay view of consumer empowerment assumes that the power is shifted from producers to consumers and, since consumers know what they want, empowerment is beneficial to consumers. This suggests that the more choices the consumer has in their purchases, the more they are able to exercise power through consumption choices (Shaw et al, 2006). However, this presumes two things: that everyone has the same capacity to make the same types of choices, and that consumers are aware of the “re-configuration of power relationships that are emerging between consumers and producers” (Shaw, et al, 2006, pg. 1062). The fact that most patients are asked to sign consent forms, such as those required by HIPAA, at the point of care is another consideration. If a patient is ill at the time of care, he may not be able to consider the privacy or technological ramifications to sharing his medical information. In this case, the patients do not have the same capacity or power relationship to make consumption choices. There has been no determination of a model to provide funding and resources for patient empowerment in e-Healthcare, either through the availability of technology or money for PHRs.

Typically empowerment is examined sociologically by Rose (1999), Foucault (White, 2002), Parsons (White, 2002), and Marx (Kamenka, 1983) as being perspectives of disparity in power, class, and control through surveillance. One way that the government and organizations can enact social control is through the control of information. Foucault, who perceives institutional medicine as a form of social control rather than healing states that surveillance of citizens is the “organization of information that can be stored by agencies and used to monitor the activities of an administered population. . . [and] in which the centralization of information about citizens is essential for social planning” (White, 2002, pg. 118-119) such as biosurveillance. Ultimately, empowerment in a sociological sense is socially constructed (Berger and Luckman, 1966) and is “an outcome of changes in fundamental structures and relations of power” (Anderson, 1996). Historically, the healthcare provider has controlled access to patient information, and this shift of control and access to the patient through PHRs signifies a drastic shift in power from the provider to the patient.

Traditionally, records in the healthcare industry have been paper-based, enabling strict accessibility to records. Due to advances in technology, managing the large amount of information involved in patient care has become much more important. Therefore, information has become the ‘key organizational currency’ for which companies need to manage and control to ‘harness the power of the politics’ which comes from such control (Davenport, et al, 1992). There is no U.S. law to state who actually owns the patient medical record. Because the control of either the paper-based medical record or electronic medical record is in the provider’s hands, traditionally, the question has been that of patient access to the record rather than ownership. There are concerns which have risen to question how access to personal health information (PHI) information will be granted. Currently, the patient gives a “blanket statement” for a single entity, but patients may not want to give such generic access across healthcare entities. Technology must be in place so that PHI is not shared electronically when the patient opts out of sharing information with specific entities. Technology such as the PHR gives a feeling of empowerment to the patient for control of their information as well as increased participation in the healthcare process. Literature supports the definition of empowerment as self-determination over one’s own life (Geller et al, 1998) as a result of having access to information and resources to enable an informed choice (Wowra et al, 1999). Empowerment holds multiple interpretations for the marketplace and business, the community, the public sector and the political system (Osborne, 1994), and over time, these interpretations have changed (Wilkinson, 1997). For e-Healthcare, this involves analyzing patient access and control of medical information for self-determination of who the information will be shared with and for what purpose. Because there is no existing theory for patient empowerment in e-Healthcare, data that are rich and detailed in description are needed to be the source and foundation for such a theory.

Research Methodology--Grounded Theory Development

Since grounded theory research methodology allows one to develop new theories where none exist, from data that is rich and detailed in description, the grounded theory approach will be utilized to examine patient empowerment in the context of e-Healthcare by analyzing meeting transcripts of various healthcare stakeholder organizations. Grounded theory is appropriate to use when there is no theory or if a phenomenon is not clearly understood, and such an approach seeks to better understand human behavior and experience (Bogdan and Biklen, 2003). Glaser and Strauss (1967) suggest that the grounded theory approach is the purposeful “discovery of theory from data systematically obtained” (pg. 2). Using the grounded theory approach, the data has been carefully examined and analyzed using the constant comparative method to begin generating concepts for theory. The constant comparative method is one in which, “both implicitly and explicitly, the analyst continually checks out his theory as the data pour in” (Glaser and Strauss, 1967, pg. 26). In essence, the researcher performs joint coding and analysis at the same time by using systematic procedures (Glaser and Strauss, 1967, pg. 102).

Table 1--Sources of Data Collection

Phase of Research	Organization	Participants	Goal
1	AHIC Consumer Empowerment Workgroup	Representatives of patient advocacy groups, U.S. DHHS, Insurance companies, vendors	To examine the concept of consumer empowerment
2	AHIC Confidentiality, Privacy, and Security Workgroup	Representatives of patient advocacy groups, U.S. DHHS, Insurance companies, vendors	To examine the concepts of privacy and security within consumer empowerment
3	NCHICA North Carolina Consumer Advisory Council on Health Information (NC CACHI)	Representatives of Patient Advocacy Groups such as groups representing Senior Citizens or HIV patients in North Carolina	To gain insight into concerns of healthcare consumers in North Carolina
4	NCHICA Provider Focus Groups	Representatives of Provider Groups from North Carolina	To gain insight into concerns of healthcare providers in North Carolina

The sources of data collection for the phases of this project are in Table 1. The American Health Information Community (AHIC) group was formed by the U.S. Department of Health and Human Services (DHHS). AHIC formed the Consumer Empowerment Workgroup and Confidentiality, Privacy, and Security Workgroups to provide recommendations to the U.S. DHHS about the adoption of PHRs and healthcare information technology and the privacy and security issues inherent in such innovations. NCHICA (North Carolina Healthcare Information and Communications Alliance) has formed a special council to engage patients (health care consumers) in providing input and feedback on topics related to health information. NC CACHI is a unique health care consumer group formed for grassroots input and participation to explore ideas and issues surrounding health information and will provide an opportunity to influence both state and national policy with regard to health care consumers’ ideas and concerns about health information and technology. NC CACHI meetings have been held monthly, since July, 2006. As part of the NC CACHI and NCHICA initiatives to gain consumer input, providers will also be interviewed during roundtable sessions to gain insight as to gaps and overlaps in the provider and consumer perspectives of healthcare information issues. Because of its leading initiatives, NC CACHI will serve as a role model for other states to create similar consumer advisory councils.

For each of these organizations, document analysis can be performed on the meeting materials, which include agendas, testimony hearings, workplans, meeting summaries, transcripts, and streaming archives. The content of these

meetings can provide a conceptual foundation for the factors driving patient empowerment in e-Healthcare by determining gaps between any differences in perspectives in the meaning of empowerment.

Preliminary Findings and Model

For this study, an initial analysis was performed on one year of AHIC meeting transcripts (Jan. 2006 to Jan. 2007), which included 495 pages of meeting notes. The documents were reviewed for content and context so that codes generated are grounded in the data. A constant comparative analysis was performed between the transcript data and the open codes to determine the context of the open codes being generated. From this analysis, six concepts and their attributes were generated—Consumers, Record, Policy, Stakeholder, Technology-Related, and Action-Related. These concepts and their attributes reveal that empowerment for patients in sharing their healthcare information between stakeholders is related to the type of medical information in the record, trust between the patient and other stakeholders, privacy and security policies such as HIPAA, and to the features of technology such as the personal health record (PHR) and the Nationwide Health Information Network (NHIN). From the frequently discussed proposed actions, the Consumer Empowerment Workgroup seems to be dedicated to the cause of encouraging empowerment issues and making recommendations to the AHIC Community Group.

Future Research

To develop a theory of patient empowerment in e-Healthcare, it will be necessary to examine further actions of the AHIC Consumer Empowerment Group, as well as its Confidentiality, Security, and Privacy Group. This will provide an initial model of patient empowerment, which can then be verified and extended through the meetings of the NCHICA Consumer Advisory Council and Provider Focus Groups. The ultimate goal of this project is to enable grassroots efforts of organizations such as NCHICA to collaborate with other states to generate effective consumer empowerment efforts so that changes in policy and technology can be encouraged for improved healthcare quality.

Abbreviated References (full reference list available upon request)

- [1] Anderson, Joan. (1996) *Empowering Patients: Issues and Strategies*. Social Sciences Medicine. 43:5, 697-705.
- [2] Bogdan, Robert C., & Biklen, Sari Knopp (2003) *Qualitative Research for Education: An Introduction to Theories and Methods*. 4th Edition. Allyn and Bacon, Boston.
- [3] Davenport, Thomas, Eccles, Robert, Prusak, Laurence. (Fall 1992) *Information Politics*. Sloan Management Review. 34:1, 53-65.
- [4] Enrado, Patty. (Dec. 18, 2006) *Washington State Unveils Health Data Exchange Map*. Healthcare IT News. Accessed Feb. 2007 at <http://www.healthcareitnews.com/story.cms?id=6068>.
- [5] Glaser, Barney, Strauss, Anselm. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine Publishing Company: Chicago, IL.
- [6] Goldman, Janlori. (1999) *Privacy and Individual Empowerment in the Interactive Age*. Visions of Privacy: Policy Choice for the Digital Age. University of Toronto Press. 97-115.
- [7] Osborne, Stephen. (1994) *The Language of Empowerment*. International Journal of Public Sector Management. 7:3, 56-62.
- [8] Shankar, Avi, Cherrier, Helene, Canniford, Robin. (2006) Consumer Empowerment: A Foucaultian Interpretation. European Journal of Marketing. 40:9/10, 1013-1030.
- [9] Shaw, Deirdre, Newholm, Terry, and Dickinson, Roger. (2006) Consumption as Voting: An Exploration of Consumer Empowerment. European Journal of Marketing. 40:9/10, 1049-1067.
- [10] White, Kevin. (2003) Foucault and the Sociology of Medical Knowledge. *An Introduction to the Sociology of Health and Illness*. Sage Publications.
- [11] Wilkinson, Adrian. (1997) *Empowerment: Theory and Practice*. Personnel Review. 27:1, 40-56.